

ADHD Treatment Response Form - For Young People by Young People

Empowering young people to be active participants in their own ADHD management and healthcare leading to the best possible outcomes

A co-production quality improvement initiative from Bedfordshire and Luton Children's Community Health Services.

What was the situation then?

Historically, ADHD medication efficacy and ADHD symptom improvement has been monitored for each young person by the adults around them (parents/carers and teachers) completing questionnaires. This includes the adults answering questions on the ADHD symptoms and behaviour of the young person. Responses to the questionnaire are evaluated using a scoring system (e.g. Connors Rating Scale - which does incur a financial cost to the service) for the paediatrician to monitor and discuss medication changes/interventions with parents/carers and the young person.

What needed to change?

The young people that use the community paediatrics service in Bedfordshire felt it was important that they were involved and able to contribute to the management of their own ADHD treatment. 'It is about us, so we should be involved'.

What did we do?

A project group was held with four young people aged 13 – 17 years (boys and girls) who have ADHD, a consultant paediatrician and a paediatric registrar, co-ordinated by the co-production lead.

The purpose was to develop a 'Treatment Response Form' designed by young people, for young people to complete. The group worked together to co-produce the form, adapted from DSM 5 ADHD symptoms, ensuring that the form was easy to use and understand, that the questions were asked in first person, and that the language was suitable and positive for young people to use, whilst also being clinically accurate as an effective assessment tool.

What happened next?

The treatment response form is now being used by young people and the community paediatrics service in Bedfordshire and Luton. Young people are able to input their perspective into the monitoring and efficacy of their own ADHD treatment and intervention by completing this questionnaire. The questionnaire is a word document, therefore accessible for free, online electronically or on a printed paper version and is quick to complete. The treatment response form has a simple scoring system* which means the individual responses indicating progress to treatment and interventions of their ADHD condition can be self-monitored by the young person. The form not only encompasses questions relating to ADHD symptoms and behaviour, but also compliance with medication, side effects, and sleep difficulties.

It also asks the young person to talk about the positives and things they enjoy doing to offer a holistic perspective.

* (Scoring system adapted from 'Effective management of attention-deficit/hyperactivity disorder ADHD) through structured re-assessment: the Dundee ADHD Clinical Care Pathway' Coghill and Seth Child Adolesc Psychiatry Ment Health (2015) 9:52; DOI 10.1186/s13034-015-0083)

What were the outcomes?

We have found that in using the Treatment Response Form as an innovative assessment tool, the paediatrician in clinic works through the completed form with the young person, thus generating a more informed discussion with the young person on areas of strength and challenge - in order to together target treatment, interventions and set goals. It has enabled both the young person, parent/carer and clinician to better understand how the young person is feeling and managing their ADHD from the young person's perspective.

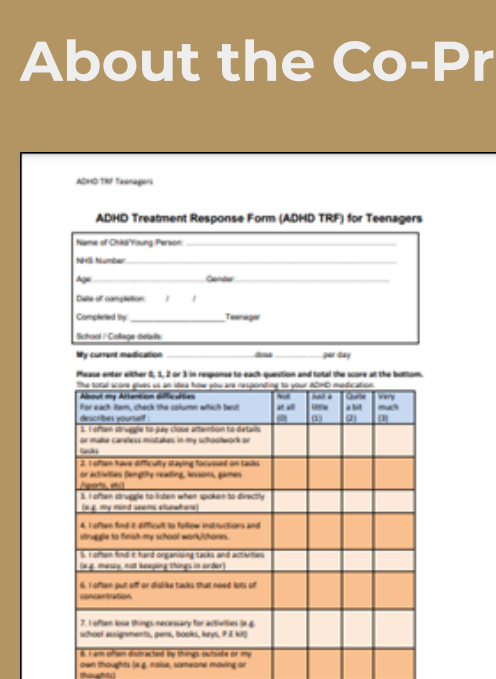
What is the impact?

The co-produced treatment response form is empowering and supporting young people to be actively involved in their own treatment and care, also aiding positive transitions into adulthood. Additionally, it reinforces and supports clinicians to value the importance of patient centred care, and the voice of the young person being central to the young person's treatment and care plan.

The feedback from the young people and their families as well as professionals has been very positive.

This free treatment response form will be the first of its kind nationally and the Bedfordshire and Luton Community Paediatric service hopes it will be shared and used across the country and internationally.

About the Co-Production Journey



The group of young people that were involved in the project group were equal partners in the designing of the form in true co-production and were engaged and proactive throughout and from the beginning. As well as spending time designing the form, the group discussed the value and benefit of being able to actively contribute to, and participate with their own healthcare, as well as health service improvements and innovations more widely.